

A faint, light-colored map of Chicago serves as the background for the slide. It shows major roads, parks, and university locations. The word "Chicago" is prominently displayed in a large, bold, serif font, with "El. 597 ft." and "of Ill. at Chicago" written below it. Other visible text includes "Highland Park", "Western Univ.", "nston", and "la Univ. Chicago".

# **MetroChicago HIE Testimony for the Illinois Health Information Exchange Authority Data Security and Privacy Committee**

*July 17, 2012*

# Introduction

- Testimony is provided on behalf of Metropolitan Chicago Healthcare Council (MCHC) at the request of the Illinois Health Information Exchange Authority
- MCHC has worked for two years to launch the MetroChicago Health Information Exchange (MetroChicago HIE)
- Marilyn Lamar is providing this testimony as outside counsel to MCHC
- Due to time limitations, this information is only a summary and does not bind MCHC, its affiliates or Participants in the MetroChicago HIE

# Overview of MetroChicago HIE Opt-Out and Consent Process

- MCHC worked with compliance officers, CIOs, attorneys and other Participant representatives to develop its approach
- General approach is opt-out – patients can decide that none of their health information will be available to other Participants through MetroChicago HIE – even for treatment
- Consensus that clinical care would be improved more by opt-out approach because more data would be available than opt-in approach
- Did not want to totally exclude patients with conditions that require specific consent

# Overview of MetroChicago HIE

## Opt-Out and Consent Process (cont.)

- It was necessary to have exceptions to the general opt-out approach for two categories of data that require special treatment under state and/or federal law:
  - “Highly Confidential PHI” (HC PHI) which requires consent under Illinois law before disclosure even for treatment purposes
  - “Excluded PHI” which requires authorization or consent under Illinois or federal law but the limited scope of use permitted after consent does not make it practical for access through MetroChicago HIE

# Overview of MetroChicago HIE

## Opt-Out and Consent Process (cont.)

- HC PHI should not be sent to MetroChicago HIE unless Participant has obtained the required patient consent
- HC PHI includes the following to comply with Illinois law:
  - HIV/AIDS testing or diagnosis information
  - Genetic testing information
- Scope of HC PHI is subject to change as laws change
- Some Participants may be subject to additional laws that would make more data HC PHI



# Overview of MetroChicago HIE

## Opt-Out and Consent Process (cont.)

- Excluded PHI should not be sent to MetroChicago HIE regardless of patient consent due to limitations on scope of use under applicable law
- Excluded PHI includes the following:
  - Mental health and developmental disability records (as defined in the Mental Health and Developmental Disability Confidentiality Act, 410 ILCS 350)
  - Psychotherapy notes (per HIPAA Privacy Rule)
  - Alcohol and substance abuse treatment information subject to 42 CFR Part 2
- Definition is subject to change as laws change

# Overview of MetroChicago HIE

## Opt-Out and Consent Process (cont.)

- Participant is responsible for the following:
  - Determine if patient record includes HC PHI and obtain patient consent or filter it out
  - Take appropriate action if consent later revoked
  - Determine if patient record contains Excluded PHI and either filter it out or do not send patient records with Excluded PHI
  - Inform patient of right to opt-out of HIE data sharing at first visit and provide opt-in reversal form if requested later
  - Promptly notify MetroChicago HIE of patients who opt-out or later opt-in

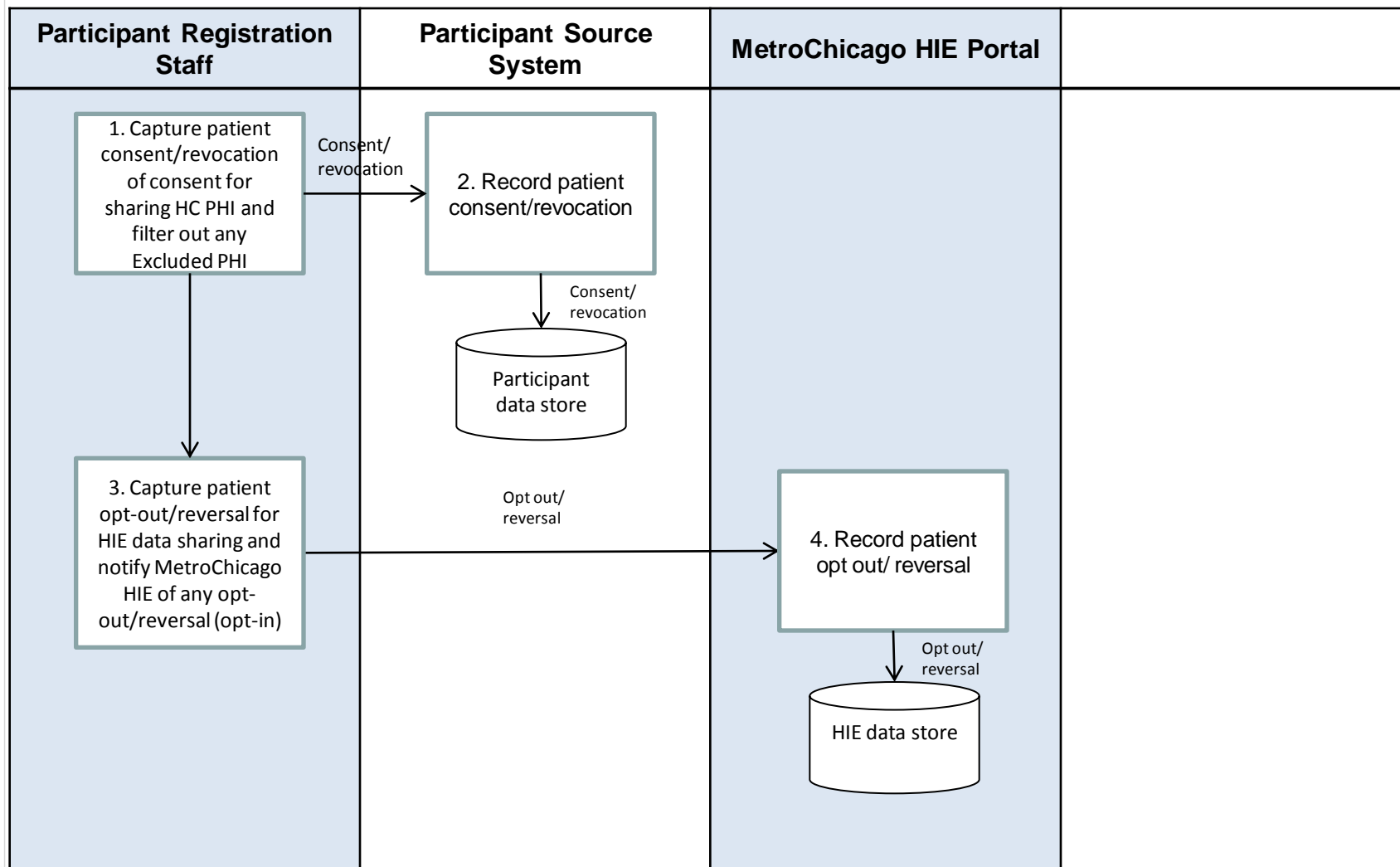
# Overview of MetroChicago HIE

## Opt-Out and Consent Process (cont.)

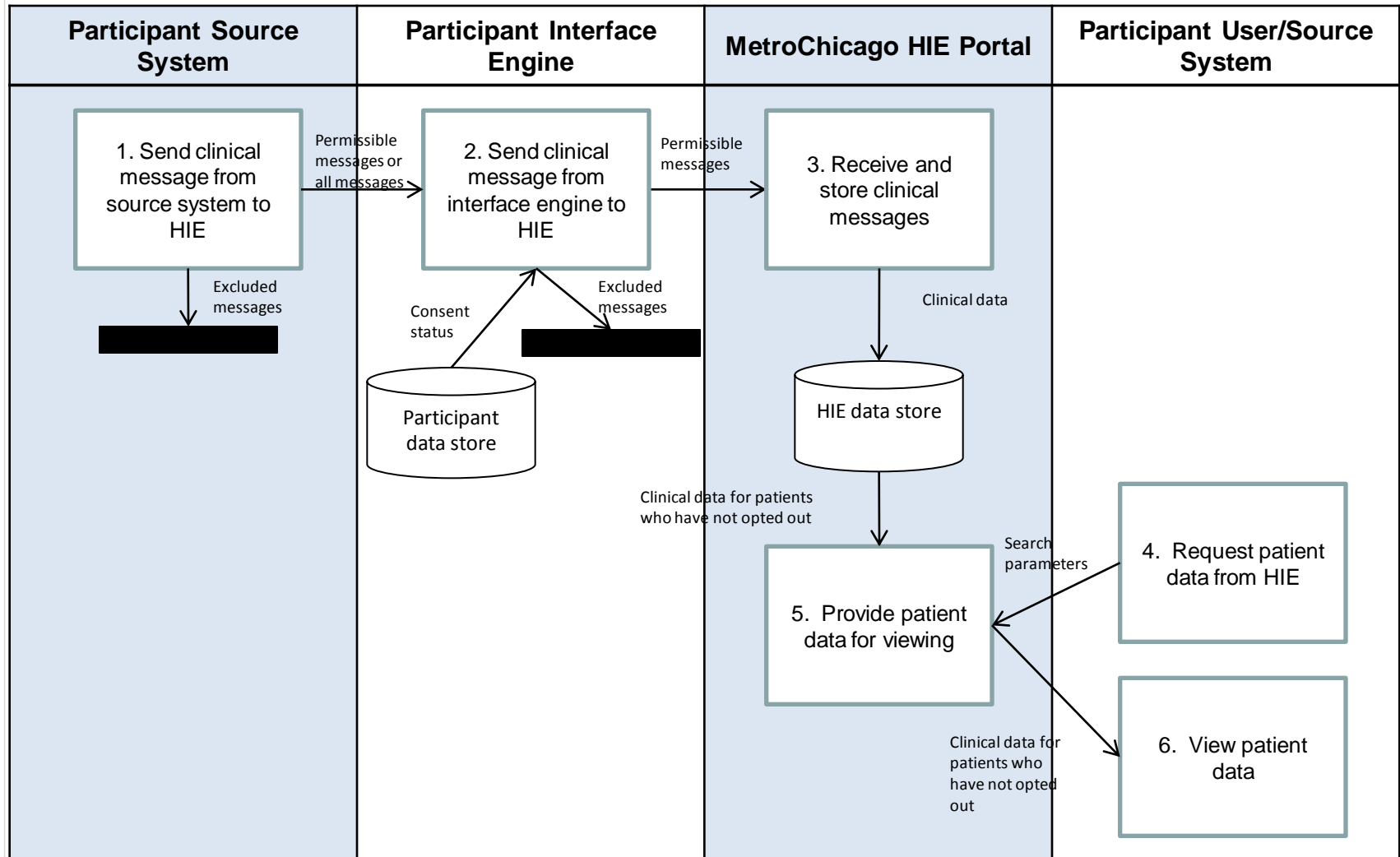
- MetroChicago HIE is responsible for the following:
  - Make patient records unavailable through HIE after notice of opt-out is received from Participant
  - Make records available if patient reverses (opts-in)
- MetroChicago HIE does not handle consents for HC PHI or filter out HC PHI or Excluded PHI
- The following diagrams are intended to illustrate how these processes will work
- Details vary in practice because Participants have some flexibility and technology limitations in how to implement



# Record Patient Consent and Opt-Out; Filter Out Excluded PHI



# Exchange Clinical Information via MetroChicago HIE



# Broadest Permissible Data Sharing Improves Patient Safety

- Granular patient choice regarding data sharing may significantly affect quality of care
  - More information in the clinician's hands improves patient safety
  - Complex granular restrictions are difficult to implement with current technology; can suppress more data than was actually requested by the patient
- “Too many holes” in patient data discourages use by clinicians, works against the coordination of care and other goals of data sharing

# Identifying Patients While Protecting Privacy

- Patient data access can be configured to help identify the correct patient and reduce unintentional disclosures
  - Reliable unique patient identifiers not available today
  - In most situations, demographic search should result in identification of *only* the right patient
  - In limited situations (*e.g.*, some ED cases), allow more latitude in locating the right patient
- Universal identifiers are desirable but difficult to implement in existing provider systems and processes in the short term

# Going deeper into the weeds of opt-out, opt-in and consent





# Details of How the Opt-Out Works

- The patient's opt-out decision at any one Participant will be effective for **all** of the patient's data in the MetroChicago HIE
  - Global - not limited to data from the Participant where the patient exercises the opt-out
  - Most important reason – clinicians believe that quality of care is improved if as much information as possible is available
  - In addition - technology does not easily permit a more granular level of opt-out

# Details of the Opt-Out (cont.)

- Offering opportunity to opt-out is required only at the first episode of care; Participant may also offer it later, but not required
- Opt-out does not expire at a specific date; may only be changed by patient
- An opt-out will be effective only on a “going forward” basis
- Participants may retain PHI they received from MetroChicago HIE and copied into their records prior to the patient’s opt-out

# Details of Reversing the Opt-Out (a Later Opt-In)

- Patient can later reverse an earlier opt-out and make all data available through HIE (global)
- To have the most data for clinical care – the data available from the HIE after the reversal will typically include PHI from period of opt-out
- Any HC PHI or Excluded PHI that was previously filtered out should still be filtered out
- The details of opt-out and reversal are disclosed to patients in Participant's forms (MetroChicago HIE provided templates)

# No “Break the Glass” in Emergencies

- Illinois does not have a general exception to allow access to patient records in an emergency (some limited exceptions in specific statutes)
- If a patient has opted-out of MetroChicago HIE, the system does not allow emergency access
- If a patient has not consented to disclosure of HC PHI, it will not be disclosed through MetroChicago HIE in an emergency
- If Excluded PHI has been filtered out, it will not be available through HIE in an emergency

# Special Issues for Excluded PHI

- Excluded PHI – primarily records from alcohol / drug abuse treatment centers and mental health / developmental disability records
- Practical problems with filtering:
  - How to filter when patient first admitted through ED and later found to have a mental health condition?
  - Exclude based on primary or secondary ICD-9 codes - sufficient?
  - Exclude all patient records from psychiatric units - too much excluded?
  - Exclude record of psychiatric medications - but sometimes given for purposes other than mental health – too much data excluded?



# Special Issues for Excluded PHI (cont.)

- Additional concerns:
  - Alcohol / substance abuse treatment centers will not be able to send (publish) data to HIE
  - Treatment often involves medications, but if data is excluded some drug interactions may not be detected and warnings noted
  - Is a new “digital divide” developing with vulnerable patients not having important data in HIEs?
- Alcohol/substance abuse treatment centers could participate to receive PHI about their patients from the HIE but they would not send (publish) data to HIE

# Other Issues for Filters

- Hard to determine what to flag and filter – *e.g.*, no list of genetic tests
- Very difficult to filter terms in text documents – *e.g.*, a filter for the term “depression” should not exclude
  - “Depression in skull” or
  - “No history of depression”
- Expensive and resource intensive to develop and apply filters – will be especially hard for small physician practices

# Conclusion

- MCHC appreciates the opportunity to present this testimony and work with the Illinois Health Information Exchange Authority to find practical solutions to improve the quality of care for Illinois patients
- We also look forward to the input of others who will testify at this hearing

Thank you